Draft Technical Brief

Number XX

Decision Aids for Advance Care Planning

Prepared for:
Agency for Healthcare Research and Quality
U.S. Department of Health and Human Services
540 Gaither Road
Rockville, MD 20850
www.ahrq.gov

Contract No.

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Suggested Citation: {USE ONLY IN FINAL REPORT. DO NOT INCLUDE IN DRAFT}

None of the investigators has any affiliation or financial involvement that conflicts with the material presented in this report.

Acknowledgments

Key Informants

Preface

The Agency for Healthcare Research and Quality (AHRQ) conducts the Effective Health Care Program as part of its mission to organize knowledge and make it available to inform decisions about healthcare. As part of the Medicare Prescription Drug, Improvement, and Modernization Act of 2003, Congress directed AHRQ to conduct and support research on the comparative outcomes, clinical effectiveness, and appropriateness of pharmaceuticals, devices, and healthcare services to meet the needs of Medicare, Medicaid, and the State Children's Health Insurance Program (SCHIP).

AHRQ has an established network of Evidence-based Practice Centers (EPCs) that produce Evidence Reports/Technology Assessments and Comparative Effectiveness Reviews to assist public- and private-sector organizations in their efforts to improve the quality of health care. Technical Briefs are the most recent addition to this body of knowledge.

A Technical Brief provides an overview of key issues related to a clinical intervention or health care service—for example, current indications for the intervention, relevant patient population and subgroups of interest, outcomes measured, and contextual factors that may affect decisions regarding the intervention. Technical Briefs generally focus on interventions for which there are limited published data and too few completed protocol-driven studies to support definitive conclusions. The emphasis, therefore, is on providing an early objective description of the state of science, a potential framework for assessing the applications and implications of the new interventions, a summary of ongoing research, and information on future research needs.

Transparency and stakeholder input are essential to the Effective Health Care Program. Please visit the Web site (www.effectivehealthcare.ahrq.gov) to see draft research questions and reports or to join an e-mail list to learn about new program products and opportunities for input. Comparative Effectiveness Reviews will be updated regularly, while Technical Briefs will serve to inform new research development efforts.

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Background

Advance care planning (ACP) for future care helps to honor patient preferences for care consistent with patient goals when illness or injury prevents adequate communication by an incapacitated patient. Less than 50 percent of severely or terminally ill patients have an advance directive in their medical record, and physicians are only about 65 percent accurate in predicting patient preferences. Decision aids that educate, provide a structured approach to thinking about choices, and prompt the patient to document and communicate preferences can help improve ACP.

Purpose

We developed a technical brief on the state of practice and current research for decision aids for adult ACP and to provide a framework for future research and effort.

Methods

We interviewed key informants representing clinicians, attorneys, consumer advocates, experts in medical law and ethics, and decision aid researchers and developers. We searched online sources for information about currently available decision aids and conducted a literature search to identify currently available research on decision aids for adult ACP as an intervention.

Findings

Numerous decision aids are widely available but are largely not represented in the empirical literature. Of the 15 published studies testing decision aids as interventions for adult ACP, most were proprietary or not openly available to the public. Decision aids tend to be constructed for the general population or designed for disease-specific conditions for narrower decision choices. Designing decision aids that are responsive to diverse philosophical perspectives and flexible to change as people gain experience with their personal illness courses remains an important concern. Future directions for effort include further research, training of ACP facilitators, reimbursement concerns, and the potential opportunities that lie in social media or other technologies.

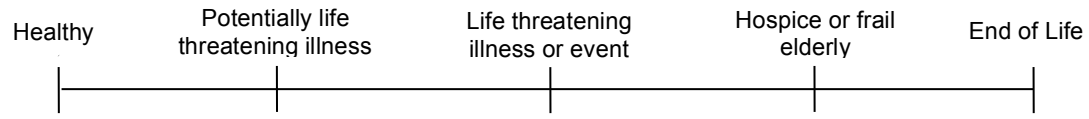
Background

Seriously ill patients' desire for life-sustaining interventions depends on their goals for care. Patients may prioritize living longer to achieve life goals, or they may wish not to be kept alive when meaningful recovery or a particular quality of life is no longer possible.[1-3] Religious and spiritual values and beliefs may also affect goals of care.[4, 5] Advanced planning for future care helps to honor patient preferences for care that is consistent with patient goals when illness or injury prevents adequate communication by an incapacitated patient.[6]

This Brief considers decision aids that support the advance care planning (ACP) process. ACP is a process of decisionmaking for future health care needs. The ACP process generally has three parts: (1) learning about anticipated condition(s) and the options for care, (2) considering those options, and (3) communicating preferences for future care, either verbally or in writing. Ideally ACP should be a part of general care planning, especially for those with complex needs. ACP can be facilitated by a health care provider but also includes use of self-administered tools or attorney-client discussions,[7] and may focus on clarifying values and choosing a person who can serve as a surrogate decisionmaker when the person is incapacitated. Thus, we define ACP decision aids broadly as a form or a tool that includes a behavioral prompt. Aids should include at least three of the International Patient Decision Aid Standards criteria of an educational component, a structured approach to thinking about choices, and a means of communicating those choices.[22, 23]

An individual's health state at the time of planning tends to determine the type of decisions considered during ACP. Figure 1 illustrates a health state continuum with several common health states that trigger ACP activities. ACP decisions vary depending on remaining life expectancy and predictability of end-of-life care needs. Understanding what information to provide to support specific ACP treatment decisions generally improves as a person moves from left to right along this continuum and familiarity with health states increases. However, some disease states have more predictable trajectories than others, and uncertainty about which health states a person will face may persist.

Figure 1. Continuum of health states during which ACP may be considered



The decision aids to support the ACP process also vary depending on where a patient falls on the spectrum provided in Figure 1. For a healthy person at the left end of this spectrum, more general decision aids regarding goals of care may be considering including: decisions for comfort versus improved function/rehabilitation versus life prolongation, and the choice of a proxy decisionmaker(s) who can communicate these values. However, for patients with a life threatening illness, decision aids for treatment or intervention specific decisions are appropriate. The types of treatment or intervention specific decisions a person may make for an ACP can include: use of cardiac compressions or defibrillator for cardiac arrest or arrhythmias, use of mechanical ventilation (particularly invasive ventilation via an endotrachial tube), use of medical

nutrition and hydration (intravenous or enteral), use of antibiotics (oral or parenteral), use of dialysis, use of pain medications or sedatives, place of abode (such as home versus nursing home), whether or not to go to the hospital, and organ donation.

Unlike other decision aids used in medical decisionmaking, ACP decision aids involve making decisions for hypothetical health states the person has not yet experienced. People who have not experienced a serious event may have a tenuous understanding about the health states for which decisions are being made. ACP decisions differ from end-of-life decisions because ACP requires people to imagine what life would be like under various conditions of disability, whereas within end-of-life decisions, the patient is directly experiencing the alternative to death. Many people exaggerate their aversion to hypothetical states of disability and hence eliminate treatment options that might lead to such disability, especially if it could be long-term.[16-19] The hypothetical disutilities for these states are consistently higher than those for persons actually experiencing the state. As a result, if treatment specific decision aids are used early in the continuum, healthy people may eliminate treatment options that, in reality, they might willingly endure.

ACP, particularly among healthy older adults, may often be undertaken outside of clinical settings. In such cases, the partners in shared decisionmaking processes include other family members, caregivers, or attorneys or other professionals rather than clinicians. A decision aid may include some prompt for the patient to record or document preferences for use by medical providers at such time as the person can no longer communicate those preferences. A decision aid may also support the choice of proxy. Just as there is considerable diversity in the populations that may be involved in ACP, there are a variety of formats and types of decision aids to assist patients and families in the ACP process. However, the empirical literature supporting decision aids for ACP is sparse.

This Technical Brief presents the "lay of the land," describing existing decision aids for ACP. We provide a framework to help readers considering which decision aid may best fit their particular environment or need. Thus, the Brief focuses on the decision aids themselves and the context within which they are used. It does not focus on the ACP decisionmaking process for patients, nor the tools or forms developed with the sole purpose of documenting advance directives or physician orders. Because of the complexity inherent to ACP for diverse populations with widely varying health states, and thus also the decision aids that support ACP, the Brief is focused on ACP for mentally and legally competent adult populations. We excluded discussion of ACP for those who have never had the ability to perform ACP, such as individuals with significant developmental disabilities and children. The contexts in which parents of gravely ill children must make decisions differ qualitatively from decisionmaking contexts for adult patients. Further, children as legal minors must rely on their parents to make decisions for them—and they may not reach the age of majority and thus the ability to form their own legally binding decisions.

Opportunity for expansion and improvement of ACP remains. A 2003 Agency for Healthcare Research and Quality summary of the literature on this topic[10] noted that less than 50 percent of the severely or terminally ill patients studied had an advance directive in their medical record, a common outcome of the advanced care planning process.[11-13, 20] Further, only 12 percent of patients with an advance directive had received input from their physician in its development,[12] moreover, physicians were only about 65 percent accurate in predicting patient preferences and tended to think patients would want less life-prolonging treatment than they actually did desire, even after reviewing the patient's advance directive.[21] Decision aids may be one way to improve

participation in ACP and the effectiveness of ACP communication.

Guiding Questions

The questions we formulated to guide the Technical Brief process are listed below.

1. What decision aids for ACP have been proposed or used in practice?
   a. What are the characteristics of the decision aid, such as the goal, mode of delivery, and settings in which it is used?
   b. How well do the decision aids meet decision aid criteria?
2. In what contexts are decision aids for ACP currently used, and what are the limitations to their use?
   a. Who generally facilitates the ACP decision process in which the decision aid is used?
   b. How are the decisions generated by the decision aid documented?
   c. How are the decision aid and/or its documentation transferred/communicated to health care settings where the healthcare activities take place?
   d. What are the implications of the combination of the health state of the person completing the decision aid, the setting in which the decision aid is completed, and whether the decisions are hypothetical or concrete?
   e. What is the legal environment and requirements for ACP for which the decision aids are used?
3. What is the current evidence on decision aids for ACP?
   a. What decision aids have been studied for effectiveness?
   b. What are the inclusion and exclusion criteria of people in studies of the effectiveness of decision aids?
   c. What were the settings examined?
   d. What outcomes were examined?
   e. Were harms or adverse effects collected in the studies; what were they?
   f. What comparators were used to examine benefits and harms?
4. What are the important issues raised by decision aids for advanced care planning and how they are used?
   a. What are the ethical considerations regarding using decision aids for ACP?
   b. How are people guided in choosing healthcare proxies?
   c. What are the implications of legal versus healthcare settings for ACP; do the decision aids adequately address the related concerns?
   d. What are possible areas of future research?

Methods

Technical Briefs are products of the Effective Health Care Program on important but underdeveloped topics in terms of the availability of high-quality studies. Technical Briefs provide an overview of key issues and describe what evidence exists. Technical Briefs do not provide synthesized evidence or grade or rate the strength of the evidence of the literature. Data presented in a Technical Brief cannot be used to develop standards or guidelines, to endorse one

practice over another, or to inform policy or payment decisions, but are useful in providing direction on next steps necessary to move the topic in the direction of the development of an evidence base from which to accomplish these goals.

We integrated information from Key Informants and a literature review. In general, responses to guiding questions 1, 2, and 4 relied on information from Key Informants as well as gray literature and published information about decision aids and the context within which they are used. Responses to question 3 are based on peer-reviewed, published studies that examined outcomes after the use of decision aids.

Discussion with Key Informants

We identified relevant key informants with the goals of efficient data collection and balanced viewpoints. We included practicing clinicians and attorneys involved in ACP, experts in medical law and medical ethics, consumer advocates, and decision aid researchers and developers. We located key informants from frequently listed and cited authors of relevant literature, Internet searches for possible candidates of relevant viewpoints, and nominations by other key informants. In cases where we were not able to identify an individual to represent a specific organization, we invited the organization to nominate an individual.

We conducted semi-structured interviews with key informants via telephone during November 2013. Interview guides for each group of key informants were developed in advance. The guides are presented in Appendix A.

Gray Literature Search

We conducted a gray literature search of federal and state government Web sites, the Ottawa Hospital Research Institute's Decision Aid Library Inventory, professional organizations, and leads from key informants, for current decision aids available to the public and in use. Appendix C provides a list of organization Web sites searched. Resources from Web sites that provide downloadable forms for advanced directive or POLST completion were excluded if they did not provide additional education or help clarify values. We also excluded resources that provided education only, without prompting action on the part of the user (e.g., ALS Association: Respiratory Decisions Guide, PBS: End of Life Dilemmas Video, Choosing Wisely: Feeding Tubes for people with Alzheimer's Disease Fact Sheet, American Health Lawyer Association: Loving Conversations Videos, Sutter VNA & Hospice: Advanced Directive Intervention List).

We also searched the Internet with Google to find information on decision aids for ACP as well as on issues and controversies regarding their use. We surveyed enrolling and ongoing clinical trials though the ClinicalTrials.gov, HSRProj, and NIH RePORTER databases, and the PCORI Web site. We also searched LexisNexis for current discussions of legal/ethical considerations and controversies.

Published Literature Search

We searched MEDLINE® via OVID, the Cochrane Library, PsychINFO, and CINAHL databases. Exact search strategies were developed in consultation with the EPC librarian. We developed an *a priori* search strategy based on relevant medical subject headings (MeSH) terms and text words. The search string is provided in Appendix B. We also searched the databases using as key words the decision aids located in the grey literature.

We screened the resulting literature for relevant published articles of empirical research. For Guiding Question 3, we searched for eligible studies that examined the use of decision aids for advanced care planning. We included studies published in English of any sample size and any design (randomized controlled trial, controlled clinical trial, uncontrolled observational trial, and case reports and series). We excluded studies that focus on implementation science questions. Further inclusion/exclusion criteria are provided in Table 1.

Table 1. Inclusion/exclusion criteria by PICOTS

Element	Included	Excluded
Population	Any adult potential patient, whether general or identified by disease	Pediatric patients, non-U.S. populations. Decisions must be for future care, not current care, and under consideration by the individual, not the proxy.
Interventions	Decision aids for future health states that include a behavioral prompt	• Religious or other edicts that specify what decision a patient should make (e.g., "artificial nutrition must be accepted" or "blood transfusions may not be accepted"). • An attorney's standard paragraph about preferences inserted into a health care directive that does not provide information about risks, benefits, or alternatives • A simple form that names a health care proxy (without providing a list of powers to choose from that would be afforded to the proxy) • Health care providers' verbal recommendations • Educational materials and research publications intended for health care professionals to help them give verbal recommendations to patients • Educational materials that only promote the process of advance care planning, without providing information to help individuals make the decisions that are part of ACP • Statutes, government policies, and health care institutional policy and procedure that describe and promote ACP or specify decision aids that must be used • Advanced planning for psychiatric care; decisions about treatment for a disease, not end of life decisions
Comparators	No aid, "traditional care," education-only material	
Outcomes	Decision agreement, confidence, patient satisfaction, knowledge, comfort, uptake. May be either patient or family/caregiver	Implementation or process measures
Timing	Decisions made for future health states	Decision of current, not future or hypothetical, end-of-life decisions for current health states
Settings	Decision aids used for health care or legal settings, whether in the presence of an attorney or do-it-yourself Web sites	

Data Organization and Presentation

We abstracted data from the published literature using standardized data abstraction tables. One reviewer collected the data and assessed the evidence against the inclusion and exclusion criteria. We did not abstract actual results from the studies.

Data from the published literature was integrated with information from the gray literature and discussions with key informants. Responses to questions 1 and 2 were formed with information from published narrative reviews, information in the gray literature, and key informant discussions. Responses to question 3 were based primarily on peer-reviewed, published literature and may be combined with information gleaned from the grey literature (e.g., information from ongoing studies). Responses to question 4 were informed by key informant discussions along with information used to address questions 1-3.

The data is presented in narrative form (questions 1, 2, and 4) and in evidence tables. We summarized the evidence into summary tables/plots by decision aid and its use. The tables are organized to provide descriptive details of identified decision aids and their conformance to decision aids criteria. For the criteria, we used the International Patient Decision Aid Standards instrument.[23]

Findings

Description of Existing Decision Aids for ACP

Existing Decision Aid Tools (Guiding Question 1)

The ideal ACP process is generally agreed on as occurring through discussions between patients and their health care providers as part of a shared decisionmaking process. Shared clinical decisionmaking involves patients and clinicians using evidence-based knowledge, weighing options against treatment goals, and consensually arriving at a clinically prudent decision concordant with patient preferences.[25, 26] Pragmatically, decision aids are generally intended to increase patient participation and/or empowerment in decisionmaking. Although ACP is within the bounds of clinical decisionmaking, it differs from many well-studied decision processes related to medical procedures (e.g. surgical or non-surgical options for cancer) because people can complete decisionmaking without health care provider involvement at all, using do-it-yourself decision aids readily available to the public. These online, do-it-yourself decision aids tend to target people with only general risks of life-threatening conditions, for whom ACP may involve considering a wide range of possible future scenarios, eliciting preferred goals of care, or choosing a proxy decisionmaker.

General decision aids for ACP are often used in conjunction with tools to help document the decisions, whether treatment-based, end-of-life based, or values-based. Preferences for health care can be documented in an Advance Directive, also known as a Living Will. Websites such as MyDirectives.com provide on-line storage of such advanced decisions. Naming of one or more proxy health care decisionmakers and their powers can be documented in a Durable Power of Attorney for Health Care or as part of a more comprehensive Advance Directive. Health care providers can record ACP results (whether from oral discussions or in an Advance Directive) into health care records a specific order (e.g., Do Not Resuscitate), or into a template most commonly called a Physician Order for Life Sustaining Treatment (POLST, found at www.polst.org). This option has the advantage of serving as standing orders.

Decision aids can also address questions regarding where patients wish to die, such as in their own homes, at hospice facilities, or in skilled nursing or hospital settings. Choice of abode can have implications for available interventions. Some types of interventions are available only in a hospital setting (e.g., surgery), while some can only be initiated in the hospital but can be managed long term at home or in a nursing facility (e.g., ventilator care). Intravenous therapies can be initiated and maintained in various settings.

Decision aids for ACP for patients with specific disease conditions can walk the undefined line between *advanced* care planning and care planning. For people with a predictable progressive disease (such as amyotrophic lateral sclerosis), chronic critical illness, or frailty, a structured approach to decisions in ACP often requires information regarding a person's prognosis. A patient may need to review data on life-expectancy and likelihood of pain or loss of function in order to decide for or against future life-prolonging therapies. In addition, a well-informed ACP often requires information on response to and added lengths of survival for potential interventions. This poses significant challenges for those creating decision aids for ACP, as prognoses are typically uncertain for individual patients and information on benefits of end-of-life treatments are rarely available for specific populations that match a patient's circumstances.

Tables 2a and 2b describe tools for ACP that are generally available. These tools were identified through the grey literature search and by key informants. The list is not exhaustive. It captures the more commonly known decision aids, or those relatively easy to find using the World Wide Web and common search engines. These tools vary in the degree to which they meet the three criteria put forth in our working ACP decision aids definition, based on the International Patient Decision Aid Standards instrument criteria:[22, 23]an education component, a structured approach to thinking about the choices a patient faces, and a way for those choices to be communicated. Tools in both tables are indexed by decision and degree to which the tool meets the three decision aid criteria.

Table 2a describes 10 general ACP decision tools for healthy older adults with an undetermined illness trajectory. The most popular ACP topics covered by tools in Table 2a include: designating a health agent or proxy decision maker (7/10), value clarification and desire for comfort care at the end of life (7/10), information on living wills or advance directives (5/10), conversation prompts for talking to loved ones or physicians about wishes (5/10), and general preferences for various life sustaining treatments (4/10). Other topics considered included: organ and tissue donation (2/10), identification of states worse than death (1/10), and preference for treatment location (1/10). Many of the general tools targeted at healthy older adults address multiple ACP topics (mode, 4 topics per tool). The breadth of the general tools is great, but the depth is compromised. This is evidenced in the degree to which the tools meet decision aid criteria. Low or medium levels of education and decisional structure are provided by most tools. These tools provide more communication of decisions because they are often attached or prompt completion of an advance directive or living well.

In contrast, Table 2b includes eight tools for individuals with a life limiting illness for which the decision trajectory is often more clearly defined. The tools in Table 2b are distinct from the general population tools in Table 2a because they are more likely to focus on one ACP topic (6/8) and they are more likely to be designed by a shared decisionmaking organization (6/8). These tools are also more likely to meet decision aid criteria. Two tools in Table 2b. (Looking Ahead: Choices for Medical Care When You're Seriously Ill and the PEACE SERIES) are similar to the tools in Table 2a, in that they cover a number of general topics without a lot of depth. Even though the tools in table 2b are more likely to be designed by decisionmaking organizations, (such as the Informed Medical Decisions Foundation and Healthwise), and to be reviewed by the Ottawa Hospital Research Institute, the tools do not appear in the published, peer reviewed literature. There is a disconnect between the grey literature tools and decision aids and the empirical literature.

Table 2a. Examples of General ACP Tools Publicly Available on the World Wide Web

Organization / Name of Tool	Topics Addressed by Tool								Developer's Description	DA Criteria			URL
	Living Will or AD	Health Agent	Life Sustaining Treatments-Multiple	States Worse than Death	Organ & Tissue Donation	Conversation Prompts	Treatment Location	Comfort Care Value Identification		Provides Education	Structured Approach	Decision Communication	
Aging with Dignity / The Five Wishes	X	X	X					X	The Five Wishes document helps individuals express care options and preferences. The advance directive meets the legal requirements in most states and is available in 20 languages for a nominal fee.	L	L	M	http://www.agingwithdignity.org/five-wishes.php
American Bar Association / Consumer's Toolkit for Health Care Advanced Planning		X	X	X	X	X		X	The tool kit does not create a formal advance directive for you. Instead, it helps you do the much harder job of discovering, clarifying, and communicating what is important to you in the face of serious illness.	L	M	M	http://www.americanbar.org/groups/law_aging/resources/consumer_s_toolkit_for_health_care_advance_planning.html
Caring Connections: National Hospice and Palliative Care Organization / End-of-Life Decisions	X	X	X						This booklet addresses issues that matter to us all, because we will all face the end of life. Advance directives are valuable tools to help us communicate our wishes about our future medical care.	M	L	L	http://www.caringinfo.org/files/public/brochures/End-of-Life_Decisions.pdf
Center for Practical Bioethics / Caring Conversations	X	X	X					X	Caring Conversations equips you with the tools you will need to communicate your wishes when you can no longer speak for yourself and advocate on your own behalf. The workbook includes a Durable Power of Attorney for Healthcare Decisions form and a Healthcare Treatment Directive form.	L	M	M	http://www.cpbmembers.org/documents/Caring-Conversations.pdf
Coalition for Compassionate Care of California / Advanced Care Planning Coversation Guide						X			The ACP conversation guide provides suggestions on how to raise the issue, responses to concerns your loved one might express, and questions to ask.	L	L	L	http://coalitionccc.org/_pdf/Conversation_Guide.pdf

Organization / Name of Tool	Topics Addressed by Tool								Developer's Description	DA Criteria			URL
	Living Will or AD	Health Agent	Life Sustaining Treatments-Multiple	States Worse than Death	Organ & Tissue Donation	Conversation Prompts	Treatment Location	Comfort Care Value Identification		Provides Education	Structured Approach	Decision Communication	
Conversation Project, Institute for Healthcare Improvement / Conversaton Starter Kit and How to Talk to Your Doctor						X		X	The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care with family members and physicians.	M	M	M	http://theconversationproject.org/wp-content/uploads/2013/01/TCP-StarterKit.pdf
Engage with Grace / Engage with Grace: The One Slide Project						X			The One Slide Project was designed with one simple goal: to help get the conversation about end of life experience started. The idea is simple: Create a tool to help get people talking. One Slide, with just five questions on it. Five questions designed to help get us talking with each other, with our loved ones, about our preferences.	L	L	L	http://www.engagewithgrace.org/
Georgia Health Decisions / CRITICAL Conditions Planning Guide	X	X			X			X	The CRITICAL Conditions Planning Guide walks you through advance care planning, beginning with meaningful conversations among your family members and resulting in the legal documentation of your preferences.	L	M	M	http://www.critical-conditions.org/preview.html
Lancashire and South Cumbria Cancer Services Network / Preferred Priorities for Care (PPC)		X					X	X	The PPC document is recommended to help identify patient preferences for end-of-life care and prevent unwanted hospital admissions at the end of life.	L	L	M	http://www.dyingmatters.org/sites/default/files/user/images/PPC%20final%20document.pdf
The Regents of the University of California / PREPARE	X	X				X		X	PREPARE is an interactive website serving as a resource for families navigating medical decision making. PREPARE is a program that can help you: make medical decisions for yourself and others, talk with your doctors, get the medical care that is right for you.	M	H	H	https://www.prepareforyourcare.org/

L=low, M=medium, H=high

Table 2b. Examples of ACP Tools for Those with Serious or Advanced Illness Publicly Available on the World Wide Web

Organization / Name of Tool	Topics Addressed by Tools										Developer's Description	DA Criteria			URL
	Living Will or AD	Health Agent	Life Sustaining Treatment	Life Support & CPR	Kidney Dialysis	Pain	Artificial Nutrition & Hydration	Conversation Prompts	Treatment Location	Comfort Care Value Identification		Provides Education	Structured Approach	Decision Communication	
American College of Physicians / PEACE Series		X				X		X		X	The Consensus Panel project convened a second group of experts to develop patient education materials and web content on end-of-life care for patients with serious or advanced illness. ACP's End-of-Life Care PEACE Series patient education brochures are available in print or to view online.	M	L	L	http://www.acponline.org/patients_families/end_of_life_issues/peace/
Healthwise / Should I have artificial hydration and nutrition							X			X	This decision aid is for patients considering artificial hydration and nutrition if or when they are no longer able to take food or fluids by mouth.	H	H	M	https://print.healthwise.net/kaiser/kpisg/Print/PrintTableOfContents.aspx?token=kpisg&localization=en-us&version=&docid=tu4431
National Cancer Institute at the NIH / Questions to Ask Your Doctor About Advanced Cancer								X			If you learn that you have advanced cancer, you may have choices to make about care and next steps. When you meet with your doctor, consider asking some of the following questions.	L	L	L	http://www.cancer.gov/cancertopics/cancerlibrary/questions/advanced-cancer
Healthwise / Should I stop kidney dialysis?					X					X	This decision aid helps patients with kidney failure who have been undergoing dialysis, and for whom kidney transplantation is not possible, decide whether to continue kidney dialysis, which will allow you to live longer or stop kidney dialysis, which will allow death to occur naturally.	H	H	M	https://print.healthwise.net/kaiser/kpisg/Print/PrintTableOfContents.aspx?token=kpisg&localization=en-us&version=&docid=tu6095

Organization / Name of Tool	Topics Addressed by Tools										Developer's Description	DA Criteria			URL
	Living Will or AD	Health Agent	Life Sustaining Treatment	Life Support & CPR	Kidney Dialysis	Pain	Artificial Nutrition & Hydration	Conversation Prompts	Treatment Location	Comfort Care Value Identification		Provides Education	Structured Approach	Decision Communication	
Healthwise / Should I receive CPR and life support				X						X	This decision aid helps patients with serious or advanced illness decide whether or not to receive CPR and be put on a ventilator if heart or breathing stops.	H	H	M	https://print.healthwise.net/kaiser/kpisg/Print/PrintTableOfContents.aspx?token=kpisg&localization=en-us&version=&docid=tu2951
Healthwise / Should I stop treatment that prolongs my life?			X							X	This decision aid helps patients with serious or advanced illness decide whether to stop treatment that prolongs your life and instead receive only hospice care, don't stop treatment that prolongs your life.	H	H	M	https://print.healthwise.net/kaiser/kpisg/Print/PrintTableOfContents.aspx?token=kpisg&localization=en-us&version=&docid=tu1430
Informed Medical Decisions Foundation / Looking Ahead: Choices for Medical Care When You're Seriously Ill	X	X	X							X	This program is for people with a serious illness that is, or may become, life threatening. This program is also for family members and caregivers. The program describes different types of medical care, such as palliative care and hospice care, and reviews various types of advance directives.	M	L	M	http://www.informedmedicaldecisions.org/imdf_decision_aid/choosing-medical-care-for-the-seriously-ill/
Ottawa Patient Decision Aid Research Group / When you need extra care, should you receive at home or in a facility?									X		This decision aid helps patients with serious or advanced illness decide whether they would like to receive care at home or in a facility	H	H	H	http://decisionaid.ohri.ca/docs/das/Place_of_Care.pdf

L=low, M=medium, H=high

Context in Which ACP Decision Aids Are Used (Guiding Question 2)

Decision aids can better standardize the ACP process across facilitators or improve its efficiency. A variety of health care professionals, legal advisors, clergy, and even trained volunteers, are available to facilitate ACP. When a decision aid is not used, the facilitator's personal knowledge and biases have more opportunity to influence decisions. The facilitator's employer may have financial incentives that influence the choice of decision aids used. For example, when a facilitator is employed or sponsored by a health care insurer, the business model of the insurer would possibly lead to decision aids that are biased towards limitations of treatment. Attorneys may find decision aids in ACP as helpful given their lack of training related to health care conditions or treatments. On the other hand, when a decision aid is used, the biases of its creators become relevant.

While attorneys typically charge for facilitation of ACP at an hourly rate, reimbursement for health care provider time related to ACP is much more complex. Physicians, nurse practitioners, and physician assistants can select billing codes based on the amount of time they spend with patients counselling regarding ACP, but only when such counselling takes up the majority of face-to-face time of an encounter. In all other cases, these providers as well as nurses, social workers, and chaplains who assist with ACP must consider facilitation of ACP as part of the overhead expense of the health care practice or institution, without separate or specific reimbursement. Several attempts to add ACP facilitation as a separate type of service into Medicare reimbursement policies have failed in Congress. This limitation in reimbursement inhibits many efforts to expand ACP, and reduces willingness to invest in decision aid development or purchase by health care institutions, except where such tools improve efficiency of ACP or advance institutions' desired outcomes of ACP (e.g., fewer deaths in hospital).

Promotion and facilitation of ACP has been strongest in settings of health care crises, when the "advance" part of ACP is hours to days. For example, the iconic SUPPORT study focused on decisionmaking in the intensive care unit.[12] Similarly, ACP is heavily promoted in regulations for nursing homes, with advocacy for decisionmaking to take place at or near admission to the facility. Alternatively, shared decisionmaking for ACP can happen earlier in the course of an illness, but after the patient develops a relationship with a trusted health care professional. Decision aids can be useful in all of these contexts, but most patients are best able to effectively utilize such a tool before crises and with a strong patient-clinician relationship.

The POLST, which translates preferences resulting from ACP into a medical order, is intended primarily for those who have life expectancies less than 1 to 2 years. The form may be placed in a healthcare record or may be given to a patient to have available in a private residence. A POLST provides explicit instructions from the signing physician to other physicians (e.g., in an emergency room), nurses, emergency medical personnel, and others. The POLST provides some legal and regulatory authorization to clinicians to provide or withhold emergency treatments, without need for further discussion or need to obtain and review an Advance Directive. About one-third of states have statutes related to POLST. Decision aids to assist with the creation of a POLST form may be specific to the types of interventions addressed in a POLST, such as cardiopulmonary resuscitation, intubation for respiratory failure, and feeding tubes.

Hospitals, nursing homes and some other health care programs are mandated to ask patients whether they have a health care directive. Recent clarifications in regulations require that nursing homes seek to determine patient preferences and enact processes to honor those preferences. Yet,

no federal or state mandates address the content or structure of ACP discussions; every state has statutes related to the documentation of preferences in health care directives.

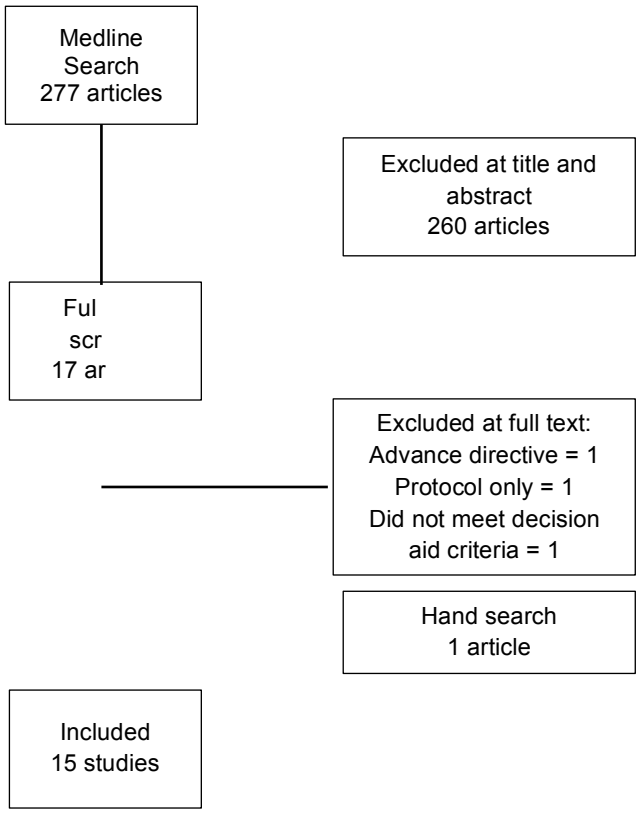
As state law governs almost all issues related to end-of-life care, content of decision aids for ACP should be consistent with a state's laws and regulations. For example, some states require that in order for a proxy to have authority regarding withholding or withdrawing a feeding tube, that preference must be explicitly stated in a healthcare directive, while other states grant a proxy discretion on that issue. Thus, an excellent decision aid for use in one state may mislead a patient's effort to document preferences in another state. This limits the ability of organizations to develop decision aids for ACP that contain a level of detail necessary to effectively complete an ACP process. Web sites such as FindLaw (http://statelaws.findlaw.com/minnesota-law/minnesota-durable-power-of-attorney-laws.html) and Caring Connections (http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3289) provide examples of available resources.

Evidence Map

Current Evidence of ACP Decision Aids (Guiding Question 3)

As previously discussed, the tools and decision aids found through grey literature search and consultation with key informants (Tables 2a. and 2b.) were not uncovered in the published literature search. The literature search yielded 340 articles. (Figure 3) Only 14 studies met the criteria for the correct patient population, intervention, and outcome measures.[15, 29-41] Studies that were excluded due to patient population (n = 18) included those that examined the use of end-of-life decision aids with families of chronic and critically ill newborns, children, and adolescents. The majority of studies were excluded based on lack of a decision aid intervention (n = 261). These studies described or evaluated how patient, surrogate, or physician characteristics (race, health literacy, disability), structural components (culture of ICU, education of physicians), economic incentives, or ethical considerations affect the end-of-life communications and care decisions, but did not include the use of a decision aid. Studies focused on decision theory or studies in which the primary outcomes of interest were the psychometric properties of a decision tool or aid were also excluded (n = 44). One study was excluded because the decision tool was for a research advance directive.[42] A protocol for a randomized control trial was also excluded, as outcome

Figure 2. Article Flow Diagram



information is not yet available.[43] An additional study was located by searching for decision aids identified in the grey literature search, bringing the total included studies to 15.

We identified an additional 10 on-going studies from ClinicalTrials.gov and HRS-Proj databases (see Appendix C). However, six of the 10 trials appear to assess videos produced by ACP Decisions.

Evaluating ACP decision aids for effectiveness is a relatively recent phenomenon, closely linked to the creation of criteria for patient decisionmaking in general. Twelve of the 14 included studies were published within the last 5 years.

Details of the included studies are summarized in Tables 3 and 4 and discussed in the next sections.

Study Designs

Studies used RCTs or case-series designs. Eight of the studies were RCTs[15, 29, 32, 37, 38, 40, 41] and seven were case-series.[30, 31, 33-36, 39] Two RCTs used a multiple treatment design.[15, 29] Harms, including patient levels of stress and anxiety or hope, have been minimally reported[31, 36, 37] and it is not clear whether harms information was systematically collected in many studies.

Patient Populations

The patient populations included in studies of decision aids for advanced care planning or end-of-life care include both patients with serious or advanced illness, and community-dwelling older adults or older adults without serious or advanced illness. This is an important distinction: the valuation of health states change with increasing age and experience of illness.[16] Physicians treating a patient with advanced cancer may want to use a tool that has been studied in, or designed for, that population. Of the 15 included studies: nine studies evaluated decision aids on community-dwelling older adults or older adult populations,[15, 29, 30, 32, 34, 35, 38, 40, 41] five studies evaluated decision aids on patients with serious or advanced illness,[33, 36, 37, 39] and one study evaluated its decision aid on both general and disease specific populations.[31] The nongeneral populations studied included patients with advanced cancers,[31, 36, 39] patients undergoing cardiac surgery,[37] and patients with Amyotrophic Lateral Sclerosis (ALS),[33] and inpatient palliative care.[44] Many studies had additional inclusion criteria for age,[15, 29, 30, 37, 38, 40, 41] language comprehension,[29, 32, 35, 38, 41] level of cognitive functioning,[15, 29, 30, 33, 38-41] availability of proxy,[15, 37, 40] and presence of target condition.[33, 36, 37, 39]

Decision Aid Modalities

Decision aids in the included studies take several forms: self-directed computer program,[31-34] enhanced information,[29] scenario-based AD,[15] value-based AD,[15] video depiction of patients with advanced disease,[30, 38, 39, 41] disease prognosis statistics,[36] structured interview,[37] interactive CD-ROM,[35] and a DVD with an accompanying booklet.[44] Ten unique decision aids were studied. One of these tools, the self-directed computer program entitled "Making Your Wishes Known," is directed at individuals, rather than organizations, and is publicly available at https://www.makingyourwishesknown.com/default.aspx. Similarly, "Looking Ahead: Choices for Medical Care When You're Seriously Ill" is publicly available in streaming video format on the Informed Medical Decisions Foundation website: http://www.informedmedicaldecisions.org/imdf_decision_aid/choosing-medical-care-for-the-seriously-ill/. However, the video based aids produced by the non-profit foundation, ACP Decisions, (http://www.acpdecisions.org/videos/), and the structured Patient Centered Advanced Care Planning interview (Gundersen Health System's Respecting Choices) are not for general public use; these tools are marketed toward specific health systems' beneficiaries. The former is

a commercial product, primarily designed for healthcare organizations; the latter was created by such an organization. The cancer prognosis statistics decision aid is available in the original article appendix,[36] and similar tools are available to physicians on the Adjuvant Web site (http://www.adjuvantonline.com/index.jsp). Three tools were described in the original articles but are not easily found in the public domain: the interactive CD-ROM,[35] the enhanced information aid,[29] the scenario based AD, and the value based AD.[15]

Comparators

The seven case-series studies did not have a comparison group by design.[30, 31, 33-36, 39] The comparison groups for the RCTs and controlled trials included control groups that received usual care,[44] groups that did not complete an advanced directive,[15] groups that were given advanced directive forms without education or with written educational materials,[32, 37] or verbal and vignette description of conditions (without video enhancement).[29, 38, 40, 41] Green et al. (2011) provides an example of a clear description of usual care for advanced directives: "This standard packet provides basic education about advanced directives, sections for assigning a surrogate decisionmaker and outlining specific end-of-life wishes, along with instructions on how to complete the form. But it does not include values clarification exercises, education about medical conditions/treatments, or a decision support tool for assisting in decisionmaking."(page 84).[32] This description is consistent with the definition of a decision aid used in this technical brief to identify appropriate gray literature tools.

Decision Aid Outcomes

Table 4 summarizes examined outcomes. The primary study outcomes include: patient satisfaction with decision aid or perceived helpfulness of decision aid (12/15), clarity regarding patient preference for comfort care (7/15), patient knowledge of advanced directives or disease process (11/15), decisional conflict or confidence in decision (4/15), patient/proxy decision concordance (2/15), effect of tool on patient stress (3/15), effect of tool on patient hope (2/15), patient/physician decision concordance (1/15), and preference stability over times (1/15). The studies report that while tools were generally well received and interpreted as helpful by patients, the effect of a decision aid on a patient's care choices and the communication of these choices to a health proxy or attending physician is mixed. Table 4 summarizes the outcomes from the reviewed tools.

Table 3. ACP decision aid studies

Study	Study Design	Population	Tool Name	Modality	Comparator
Volandes et al., 2012[39]	Case series	Patients with advanced cancers	ACP Advanced Cancer Video	Video	Patients served as own control, before and after viewing video (all subjects received verbal description of care choices)
Deep et al., 2010[30]	Case series	Community dwelling older adults	ACP Advanced Dementia Video	Video	Patients served as own control, before and after viewing video (all subjects received verbal description of care choices)
Volandes et al., 2009[40]	Randomized controlled trial	Community dwelling older adults	ACP Advanced Dementia Video	Video	Patients randomized to verbal description only or verbal description with video decision aid
Volandes et al., 2009 (BMJ)[41]	Randomized controlled trial	Community dwelling older adults	ACP Advanced Dementia Video	Video	Patients randomized to verbal description only or verbal description with video decision aid
Volandes et al., 2011[38]	Randomized controlled trial	Community dwelling older adults	ACP Advanced Dementia Video	Video	Patients randomized to verbal description only or verbal description with video decision aid
Smith et al., 2011[36]	Case series	Patients with advanced cancers	Adjuvant	Disease prognosis and probability statistics	Patients served as own control, before and after using decision aid
Allen et al., 2008[29]	Randomized controlled trial	Community dwelling older adults		Enhanced information on life-sustaining treatment risks, benefits, and alternatives	Patients randomized to enhanced information, medical information stimuli, and the LSPQ vignettes, or LSPQ vignettes only
Ditto et al., 2001[15]	Randomized controlled trial	Community dwelling older adults	Health Care Directive (HCD) Valued Life Activities Directive (VLA)	Scenario-based AD Value-based AD	Patients randomized HCD no discussion, HCD with discussion, VLA no discussion, VLA with discussion, or no advanced directive
Matlock et al., 2011[44]	Randomized controlled trial	Inpatient Palliative Care	Looking Ahead: Choices for medical care when you're seriously ill	Booklet and DVD	Patients randomized to usual palliative consult services or usual care and the decision aid
Murphy et al., 2000[35]	Case series	Community dwelling older adults	Making Decisions About Health Care	Interactive CD-ROM	Patients served as own control, before and after using decision aid
Green et al., 2009[31]	Case series	Community dwelling older adults Patients with cancer	Making Your Wishes Known: Planning Your Medical Future	Self-directed computer program	Patients reported satisfaction and enhanced knowledge with use of aid.
Green et al., 2011[32]	Randomized controlled trial	Community dwelling older adults Medical students	Making Your Wishes Known: Planning Your Medical Future	Self-directed computer program	Medical students and patients dyads were randomized to usual care or decision aid arms.

Study	Study Design	Population	Tool Name	Modality	Comparator
Hossler et al., 2011[33]	Case series	Patients with Amyotrophic Lateral Sclerosis (ALS)	Making Your Wishes Known: Planning Your Medical Future	Self-directed computer program	Patients served as own control, before and after using decision aid
Levi et al., 2011[34]	Case series	Community dwelling older adults	Making Your Wishes Known: Planning Your Medical Future	Self-directed computer program	Evaluation of decision aid's ability to appropriately guide physician making
Song et al., 2005[37]	Randomized controlled trial	Patients undergoing cardiac surgery	Patient-Centered Advanced Care Planning (PC-ACP)	Structured interview	Patients randomized to usual AD care (information packet and access to pastoral care facilitator) or decision aid

Table 4. Outcomes examined by ACP decision aid studies

Study	Population	Modality	Tool Name	Satisfaction / Perceived Benefits of Tool	Desire for Comfort Care	AD or Disease Knowledge	Preference Stability Over Time	Decisional Conflict/ Confidence in Decision	Pt. / Proxy Concordance	Pt. / Doctor Concordance	Pt. Hope	Pt. Stress or Anxiety
Volandes et al., 2012[39]	Patients with advanced cancers	Video	ACP Advanced Cancer Video	+	NE	+						
Deep et al., 2010[30]	Community dwelling older adults	Video	ACP Advanced Dementia Video	+	+	+						
Volandes et al., 2009[40]	Community dwelling older adults	Video	ACP Advanced Dementia Video	+	+	+						
Volandes et al., 2009 (BMJ)[41]	Community dwelling older adults	Video	ACP Advanced Dementia Video	+	+	+	+					
Volandes et al., 2011[38]	Community dwelling older adults	Video	ACP Advanced Dementia Video	+	+							
Smith et al., 2011[36]	Patients with advanced cancers	Disease prognosis and probability statistics	Adjuvant	+		+					NE	NE
Allen et al., 2008[29]	Community dwelling older adults	Enhanced Information on life-sustaining treatment risks, benefits and alternatives			+AA* White			-				
Ditto et al., 2001[15]	Community dwelling older adults	Scenario-based AD Value-based AD	Health Care Directive (HCD) Valued Life Activities Directive (VLA)	+	NE				NE			
Matlock et al., 2011[44]	Inpatient Palliative Care	Booklet and DVD	Looking Ahead: Choices for medical care when you're seriously ill	+		NE		NE				
Murphy et al., 2000[35]	Community dwelling older adults	Interactive CD-ROM	Making Decisions About Health Care	+		+						
Green et al., 2009[31]	Community dwelling older adults Patients with cancer	Self-directed computer program	Making Your Wishes Known: Planning Your Medical Future	+		+					NE	NE

Study	Population	Modality	Tool Name	Satisfaction / Perceived Benefits of Tool	Desire for Comfort Care	AD or Disease Knowledge	Preference Stability Over Time	Decisional Conflict/ Confidence in Decision	Pt. / Proxy Concordance	Pt. / Doctor Concordance	Pt. Hope	Pt. Stress or Anxiety
Green et al., 2011[32]	Community dwelling older adults Medical students	Self-directed computer program	Making Your Wishes Known: Planning Your Medical Future	+		+						
Hossler et al., 2011[33]	Patients with Amyotrophic Lateral Sclerosis (ALS)	Self-directed computer program	Making Your Wishes Known: Planning Your Medical Future	+		+						
Levi et al., 2011[34]	Community dwelling older adults	Self-directed computer program	Making Your Wishes Known: Planning Your Medical Future					+		+		
Song et al., 2005[37]	Patients undergoing cardiac surgery	Structured interview	Patient-Centered Advanced Care Planning (PC-ACP)			-		-	+			NE

AD= advance directive. NE=not evaluated. AA=African American. +The study reported positive findings for that outcome. – The study reported negative findings for that outcome.

*African Americans differed from whites in preferences for receiving comfort care versus life sustaining care.

Evaluating ACP Decision Aids

The International Patient Decision Aid Standards (IPDAS) Collaboration has developed criteria for evaluating the quality of a decision aid (http://ipdas.ohri.ca/IPDAS_checklist.pdf). In Table 5, we use the broad categories from the IPDAS checklist to identify the index question and briefly evaluate the quality of the decision aid content and development for the decision aid tools from Table 2 and the published decision aids presented in Table 3.

An important component for the IPDAS decision aid evaluation is having an index decision. The main goal of five of the tools identified in Table 1 was to prompt discussion of individual values for end-of-life care with loved ones and physicians. Motivating people to have advanced planning conversations with loved ones is important. However, these conversation tools do not focus on a decision(s) and are, therefore, not evaluated.

Only three tools from the published literature could be evaluated using the IPDAS standards (Adjuvant, Making Your Wishes Known: Planning Your Medical Future, and Looking Ahead: Choices For Medical Care When You're Seriously Ill). The ACP Decisions videos depicted a woman with advanced Alzheimer's disease, but did not focus on a decision. A few of the decision aids were not publicly available.[15, 29, 35] The Respecting Choices, Patient-Centered Advanced Care Planning (PC-ACP) interview is proprietary.

The general decision aid tools that helped people chose a proxy and make advanced directive decisions provided less information about the index decisions than the condition specific aids. For the most part, these advanced planning tools targeted at the general public were less likely to help people deliberate on their decision. One notable exception is the interactive online resource, PREPARE. PREPARE helps patients deliberate and communicate their decisions, while providing considerable information and video examples for each decision. The decision aid tools that focus on only one decision point are more likely to provide high levels of information and help the user deliberate, or come to his or her decision. Five of the decision-specific tools have been previously reviewed by the Ottawa Patient Decision Aid Research (OPDAR), using the IPDAS criteria. While the content criteria can be evaluated by an individual viewing the tool, the development criteria is less apparent on most of the organization websites. The five tools reviewed by OPDAR had this information available in their decision aid summaries, available on their Web site: http://decisionaid.ohri.ca/index.html.

Applying the IPDAS criteria to the decision aid tools highlights the general lack of effectiveness information. An effective decision aid leads to decisions that are informed and consistent with the decisionmaker's values. Few tools on the OPDAR Web site have met all effectiveness criteria. Generally available decision aids do not provide information to evaluate whether effectiveness has been assessed. For the decision aids found in the published effectiveness literature, the outcome measures are not effectiveness measures, as measured by the IPDAS, but measures of satisfaction and desire for comfort care over life-sustaining treatment. If comfort care is the choice that is consistent with the informed consumer's values and wishes, then the tool is effective. Some informed consumers will have value systems that lead them to choose life sustaining care.

Key informants highlighted a fairly specific set of criteria important to assess decision aids. The first criterion is whether the decision aids are balanced, informing but not selling particular philosophical stances or specific decisions. The second criterion is whether decision aids present narratives of people who have gone through the experiences, particularly if several voices provide different perspectives to enhance the decision aid balance. The third criterion is making

core facts available to reduce the likelihood of overestimating the value of interventions and the odds of good outcomes. Presenting relevant facts effectively and accessibly is important.

Table 5. Evaluating ACP decision aids

	Index Decision				Decision Aid Content						Decision Aid Development					Effectiveness
Name of Tool	Selection of health proxy	Preference for multiple ACP decisions	Preference for a specific life-prolonging treatment	Preference for place of care	Provide information	Present probabilities	Clarify patient values	Guide decision deliberation	Guide decision communication	Present balanced information	Systematic development	Cite scientific evidence	Disclose COI	Use plain language	Decisions are informed and value based
The Five Wishes	X	X			L		X		X					X	
Consumer's Toolkit for Health Care Advanced Planning	X	X			M		X		X						
Caring Connections: End of Life Decisions	X	X			M		X								
Caring Conversations	X	X			M		X	X	X					X	
CRITICAL Conditions Planning Guide	X	X			M		X		X					X	
'Thinking Ahead' – GSF Advance Care Planning Discussion	X	X		X			X		X					X	
PREPARE	X	X			H		X	X	X	X	X				
Should I have artificial hydration and nutrition?			X		H		X	X	X	X	X	X	X	X	M
HD: Values History Form	X	X			H		X		X						
Should I stop kidney dialysis?			X		H	X	X	X	X	X	X	X	X	X	M
Should I receive CPR and life support?			X		H	X	X	X	X	X	X	X	X	X	M
Should I stop treatment that prolongs my life?			X		M		X	X	X	X	X		X	X	M
Looking Ahead: Choices for Medical Care When You're Seriously Ill	X	X			M		X								
When you need extra care, should you receive it at home or in a facility?			X		M		X	X	X	X			X	X	
Adjuvant			X		H	X		X		X	X		X	X	M
Looking Ahead: Choices for Medical Care When You're Seriously Ill	X	X			M		X			X					
Making Your Wishes Known: Planning Your Medical Future	X	X			M		X		X	X	X		X		M

X=item was identified as present or met. L= Low; M = Medium; H = High.

Summary and Implications

Important Issues Raised by the Technology (Guiding Question 4)

Conversations with key informants raised several important issues regarding decision aids and their place in ACP.

As shown in the findings, there are two broad functions of decision aids in ACP: 1) to identify a proxy decisionmaker, and 2) to decide in advance on preferences for care in specific situations. Many key informants and some advance care planning Web sites promote a population-specific approach, whereby only those with advanced illness or high risk of catastrophic health events are encouraged to become educated on the specifics of their condition and options for life-sustaining treatments. That population is then encouraged to name a health care proxy decisionmaker and assure that person is aware of preferences for care. All other people, who have more uncertain future health needs, are simply encouraged to choose and document a health care proxy decisionmaker. Several key informants noted the difficulty of determining what information to provide that will best serve the needs of people unless the target audience is clearly defined, and which is often easiest for disease-specific tools. This population approach in in contrast to public policy and most common models of ACP which are based upon a single model applied to all adult populations. Patients become informed, develop preferences, and document their choice of proxy decisionmaker and/or write their preferences in a health care directive. A population approach leads to population-specific decision aids, with general tools for the broader population and disease-specific tools for those with advanced illness.

Several key informants suggested that for people with serious or chronic critical illnesses, ACP functions best as an integrated part of an overall care plan. In such cases, advanced care decisions would be discussed in the context of other evaluated care options and based upon the options available in the chosen care setting. The nature and extent of available services vary by location (e.g., nursing home vs. hospital). Care decisions can imply a willingness to move to a more (or less) intensive environment (e.g., do not hospitalize instructions). Without explicit information about which services are available in various settings, patients may express preferences for or against therapies and for or against settings that turn out to be incompatible or may express preference to decline certain therapies on a mistaken assumption that such an intervention can only be offered in the hospital.

In cases of persons with established conditions, ACP decisions need to be based, in part, on knowledge of prognosis. An important role of decision aids is to provide methods to inform patients about their prognosis, and the implications their prognosis might have on their health care decision. Ideally, patients would be presented with information on the expected natural history of the condition(s) they currently have. This information would be combined with decisions and preferences based on the efficacy of various life sustaining interventions to change the course of illness. Potentially, the clinical and administrative databases do exist (i.e., Big Data) that could provide current and continually updated information or prognosis and treatment efficacy in advanced illness, but it remains a challenge to create interactive or patient-specific tools to assist patients and clinicians in estimating probabilities of benefit of interventions in various circumstances near the end of life. Prognosis and planning is even more challenging for diseases with less certain trajectories (such as heart disease or dementia versus metastatic cancer) and thus harder for providers to know when and what to talk about, and harder for designers of decision support materials to know what to include in a decision aid.

The need for such information in decision aids becomes apparent in situations where patients and families anticipate future difficulties with maintenance of oral nutrition. The likelihood of such a problem varies across diseases, such as Alzheimer's, Parkinson's, strokes, ALS, and esophageal disorders. The benefits of medical nutrition, such as enteral feeding through a gastrostomy tube, also vary significantly depending on the cause of poor oral intake. Without data-rich decision aids, patients with early Alzheimer's might mistakenly believe there is therapeutic benefit from enteral feeding (there is none found in multiple studies), while those with primary swallowing disorders might mistakenly extrapolate information from populations with dementia to underestimate the benefits of this therapy for their condition.

How questions are posed by decision aids can affect responses. Several key informants noted discomfort with some ACP videos because they portrayed patients with health states the viewers may expect for themselves as moribund or vacant. They expressed concern the images could be overly frightening to people of generally good health who are far from experiencing such diminished health states, and thus bias viewers towards less care than they may otherwise have chosen. Providing accurate information and frames that portray a realistic range of health state experiences is challenging, and achieving a "good balance" may very well be in the eye of the beholder. Other key informants found video vignettes particularly important for engaging people in the decisionmaking process for ACP and helping them envision possible future health states they may have otherwise avoided. However, the use of heuristics for decisionmaking tends to increase as decisional complexity increases, such as when a person's emotional intensity state is high.[45]

Key informants suggested taking the "A" out of ACP by making ACP an on-going process rather than a one-time decision to be documented. Certainly these decisions need to be revisited as a patient's condition deteriorates. The Gold Standards Framework Tool "Thinking Ahead – GSF Advance Care Planning Discussion" guide is one example of a tool intended as a dynamic document to be adapted and reviewed as needed. However, other key informants suggested that having people complete at least one ACP is still urgently needed, that it takes precedence over creating decision aids to support dynamic ACPs.

Several key informants also noted the ethical concern that decision aids be tolerant of the many philosophical perspectives that people may bring to the process. In a country as diverse as the US, decision aids need to be culturally and spiritually sensitive to traditions and supportive of nuanced decisions. Decision aids need to be flexible to the process and not solely focus on the outcome.

The use of computer-based decision aids and ACP documentation tools was a concern to key informants due to the potential for access problems there is exclusive or over-reliance of web-based tools. This concern held as well for decision aids and tools that were not free and easily available to the public. Certain patient populations without easily accessed computer resources are at a disadvantage. ACP facilitators may be one way to provide access to ACP decision aids for vulnerable populations by bringing the decision aid materials or resources to the patients.

Key informants held various opinions on the role of specialized facilitators and who would best fulfill such a role. Differences could concern the specific professional training (e.g., Social Workers and Nurses versus Clergy versus Physicians versus Lawyers) or might reflect specialized training in ACP facilitation regardless of discipline. In the latter case, the skills the facilitator brings to the encounter, rather than the role, is highlighted. A prime skill noted is the ability to respect the decision made, whether or not the facilitator agrees with it. At the same

time the greater the demand for special status, the greater the tendency for problems with access issues due to increased costs.

While providers are often the automatic default when considering facilitators, several key informants noted that physicians often are the most challenged to facilitate conversations; reasons proffered ranged from physicians having personal difficulty with talking about dying and considering end-of-life decisions when all their training and motivation is toward cure and life prolongation, to more traditional concerns regarding patriarchal attitudes.

Although most ACP tools include choice of proxy decisionmaker as an element of the tool, key informants noted a lack of decision aids designed to help people with the decision of choosing a proxy well. However, a couple of attempts in that direction have been made. One key informant noted that Caring Connections provides some links on their webpage, but does not directly take up the task. Key informants noted that, in addition to selecting a proxy, in-depth conversations are needed between people and their proxies in order to establish clarity about the persons' values and outcome preferences. These conversations give the proxy a sense of confidence regarding representing the patient to the health care providers at the time when end-of-life decisions must finally be made. One key informant noted that voice recordings of the patient's preferences and values can be a very powerful way to make the patient's wishes "real" during the difficult times.

Ultimately, decision aids provide a structure that allows people to deeply consider and document their preferences and support important relationships. A well-considered and communicated preference supports the physician to feel assured and at peace about the ethics of treating or stopping treatment when the time is right. Well-considered and communicated preferences provide closure to family and loved ones who will live longer with the consequences.

Next Steps

Future directions for efforts to improve ACP decision aids fall into four categories.

1. Research is needed regarding:
   - Well-designed, validated, tools that are easily accessible, readable, and understandable. While there has been some progress in this regard, much remains to be done.
   - Comparison of various decision aids, including patient and provider satisfaction, impact on preferences stated, and efficiency of the ACP processes. These studies might include attention to who facilitates these decisions and how.
   - Development of better, more individualized predictive models for life expectancy that can be incorporated into ACP decision aids.
   - Effectiveness of various end-of-life interventions in specific populations, to create better educational materials about these interventions for ACP decision aids.
   - Since location of care is sometimes a dominant preference in ACP, decision aids could be designed to enable patients to work backwards from their preferred site of care to then decide which therapies they might accept in that setting.
   - Since professionals supporting ACP may include clinicians, lawyers, social workers, and clergy (or none), decision aids should be evaluated for the context within which they are intended to be used.

2. Training of current or future facilitators of ACP (health professionals, attorneys, clergy, social workers) is needed regarding:
   - Shared decision making, using decision aids
   - Use of decision aids, to reduce variation in the process of ACP
   - Value of decision aids, to improve clarity of verbal and written communication
   - Increased understanding of how the background of the decision facilitator affects the decision processes.

3. Use of social media and other technologies provide further opportunities to improve decision aid development.
   - Create decision aids that provide personal narratives based on patient experiences in various health conditions and after receiving life prolonging therapies. Several of the decision aid resources presented here have started this process. More could be accomplished using social media to democratize the process of sharing and collecting patient experiences.
   - Social media and other big data sources may also allow access to more fine-grained individualized information to help improve not only prognostic abilities, but also to illuminate what choices people have made and the resulting course. People like to know how other people have chosen and behaved.

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Appendix A: Interview Guides for Key Informants

Questions for experts/researchers/provider organizations/practicing clinicians

a. What decision aids do you use in advanced care planning?
b. What specific ACP tools and aids characterize your program? (May we see them?)
c. What do you see as the strengths and weaknesses of the decision aids you have used? The barriers and facilitators of using the decision aids?
d. Grey literature: which professional organizations are important to consult regarding:
    i. Tools
    ii. Preliminary study findings
e. Review/comment on definitions of ACP and decision aid models
f. What types of research are needed most? What outcomes? What designs? When should outcomes be measured (length of followup)?
g. What format works best in your experience?
h. Which health care directive form do you prefer?

Questions for patient advocates, families, caregivers

a. What information do patients need to know when planning advanced care?
b. Does that information change based on your level of health?
c. What do you view as the advantages/disadvantages of advance planning?
d. How did the decision aid help with the planning process?

Questions for ethicists/clergy/law

a. What do you consider important ethical considerations that need to be addressed with regard to ACP and decision aids?
b. How do decision aids help or change the dynamics of the ACP process itself, and, if conducted as a dialogue, discussions between patients, family members, and providers?
c. What information do you believe is most needed by people considering ACP?
d. What kinds of research would be most useful? What outcomes?
e. To what extent should the health care professional facilitating the conversation give advice (person as decision aid)?

Appendix B: Published Literature Search Strategy

We searched MEDLINE using the algorithm listed below. We adjusted the algorithm to also search the Cochrane Library, PsychINFO, and CINAHL databases.

Database: Ovid MEDLINE® <1946 to August Week 4 2013> Search Strategy:

1	exp Advance Care Planning/ (6874)
2	exp Advance Directives/ (6012)
3	"advanced care plan*".ti. (16)
4	"advance* care plan*".m_titl. (373)
5	(advance* adj2 directive*).ti. (1466)
6	"living will*".m_titl. (534)
7	"end of life".mp. (10604)
8	exp Decision Support Techniques/ (61793)
9	exp Decision Support Systems, Clinical/ (5097)
10	decision aid*.mp. (1298)
11	decision tool*.mp. (339)
12	decision support.mp. (20794)
13	instrument*.ti,ab. (168622)
14	intervention*.ti,ab. (512195)
15	program*.ti,ab. (534141)
16	exp *Decision Making/ (53054)
17	12 or 13 or 14 (1126467)
18	15 and 16 (6792)
19	7 or 8 or 9 or 10 or 11 or 17 (77632)
20	1 or 2 or 3 or 4 or 5 or 6 (16119)

Appendix C: Organization Websites Searched for Grey Literature

Organization
Aging with Dignity
Allina Health
ALS Association
American College of Physicians
Caring Connections
Center for Advanced Illness Coordinated Care, National Hospice and Palliative Care Organization
Coalition for Compassionate Care of California
Conversation Project, Institute for Healthcare Improvement
Deathwise
Engage with Grace
Gold Standards Framework
Gundersen Health System, Respecting Choices
Healthwise
Henry Ford Health System
Honoring Choices Minnesota
Informed Medical Decisions Foundation
Lancashire and South Cumbria Cancer Services Network
Lifecare Directives, LLC
National Cancer Institute at the NIH
National Hospice and Palliative Care Organization
National POLST Paradigm Task Force
Ottawa Patient Decision Aid Research Group
PBS Religion & Ethics Newsweekly
Renal Palliative Care Initiative
Robert Wood Johnson Foundation, Promoting Excellence in End of Life Care
Sutter VNA and Hospice
The Huntington's Disease Workgroup of Promoting Excellence in End-of-Life Care
The Regents of the University of California

Appendix D: Evidence Tables

Table D1. Gathered examples of commonly used or accessible decision aids

Name of Tool/ Organization	Target Population	Description	Purpose of Tool	Tool Format
The Five Wishes/ Aging with Dignity	General planning before a medical event or terminal illness	The Five Wishes document helps individuals express care options and preferences. The advance directive meets the legal requirements in most states and is available in 20 languages for a nominal fee.	AD education and completion	Order hard copy or complete online. Educational DVDs available.
Consumer's Toolkit for Health Care Advanced Planning/ American Bar Association	General planning before a medical event or terminal illness	The toolkit does not create a formal advance directive for you. Instead, it helps you do the much harder job of discovering, clarifying, and communicating what is important to you in the face of serious illness.	AD education Clarify values	Downloadable guide
End-of-Life Decisions/ Caring Connections	General planning before a medical event or terminal illness	This booklet addresses issues that matter to us all, because we will all face the end of life. Advance directives are valuable tools to help us communicate our wishes about our future medical care.	AD education	Downloadable guide
Caring Conversations/ Center for Practical Bioethics	General planning before a medical event or terminal illness	Caring Conversations equips you with the tools you will need to communicate your wishes when you can no longer speak for yourself and advocate on your own behalf. The workbook includes a Durable Power of Attorney for Healthcare Decisions form and a Healthcare Treatment Directive form.	AD education and completion Conversation guide	Downloadable guide
Advanced Care Planning - Conversation Guide/ Coalition for Compassionate Care of California	General planning before a medical event or terminal illness	The ACP conversation guide provides suggestions on how to raise the issue, responses to concerns your loved one might express, and questions to ask.	Conversation guide or prompts	Downloadable guide
Conversation Starter Kit and How to Talk to Your Doctor/ Conversation Project, Institute for Healthcare Improvement	General planning before a medical event or terminal illness	The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care with family members and physicians.	Conversation guide or prompts	Online resource and downloadable guides
Engage with Grace: The One Slide Project/Engage with Grace	General planning before a medical event or terminal illness	The One Slide Project was designed with one simple goal: to help get the conversation about end-of-life experience started. The idea is simple: create a tool to help get people talking. One Slide, with just five questions, is designed to help get us talking with each other and with	Conversation guide or prompts	Web page with downloadable slide

Name of Tool/ Organization	Target Population	Description	Purpose of Tool	Tool Format
		our loved ones about our preferences.		
CRITICAL Conditions Planning Guide/ Georgia Health Decisions	General planning before a medical event or terminal illness	The CRITICAL Conditions Planning Guide walks you through advance care planning, beginning with meaningful conversations among your family members and resulting in the legal documentation of your preferences.	AD education and completion Conversation guide	Order hard copy or download
Preferred Priorities for Care (PPC)/ Lancashire and South Cumbria Cancer Services Network	General planning before a medical event or terminal illness	The PPC document is recommended to help identify patient preferences for end-of-life care and prevent unwanted hospital admissions at the end of life.	Document patient wishes	Downloadable guide
PREPARE/The Regents of the University of California	General planning before a medical event or terminal illness	PREPARE is an interactive Web site serving as a resource for families navigating medical decision making. PREPARE is a program that can help you: make medical decisions for yourself and others, talk with your doctors, and get the medical care that is right for you.	AD education and completion Conversation guide	Video/interactive online resource
PEACE Series/ American College of Physicians	Patient with serious/ advanced illness	The Consensus Panel project convened a second group of experts to develop patient education materials and web content on end-of-life care. ACP's End-of-Life Care PEACE Series patient education brochures are available in print or to view online.	Conversation guide or prompts	Downloadable brochures
Should I have artificial hydration and nutrition?/Healthwise	Patients considering artificial hydration and nutrition if or when they are no longer able to take food or fluids by mouth	This decision aid helps patients decide whether or not to have artificial hydration and nutrition.	Education, value determination, document decision	Online resource
Questions to Ask Your Doctor About Advanced Cancer/ National Cancer Institute at the NIH	Patients with advanced cancer	If you learn that you have advanced cancer, you may have choices to make about care and next steps. When you meet with your doctor, consider asking some of these questions.	Conversation guide or prompts	Online resource
Values History Form/ Huntington's Disease Workgroup of Promoting Excellence in End-of-Life Care	Patients with Huntington's Disease	This document, when completed and attached to a Huntington's Disease patient's Advance Directive, gives the appointed Health Care Agent and the physician a specific and comprehensive guide to desired care.	Guide for HD patients, proxies, and physicians	Downloadable 70-page document with scenarios and resources
Should I stop kidney dialysis?/Healthwise	Patients with kidney failure who have been undergoing dialysis, and for whom kidney transplantation is not possible	This decision aid helps patients decide whether to continue kidney dialysis, which will allow you to live longer, or stop kidney dialysis, which will allow death to occur naturally.	Education, value determination, document decision	Online resource

Name of Tool/ Organization	Target Population	Description	Purpose of Tool	Tool Format
Should I receive CPR and life support?/ Healthwise	Patients with serious/ advanced illness	This decision aid helps patients decide whether or not to receive CPR and be put on a ventilator if heart or breathing stops.	Education, value determination, document decision	Online resource
Should I stop treatment that prolongs my life?/ Healthwise	Patients with serious/ advanced illness	This decision aid helps patients decide whether to stop treatment that prolongs life and instead receive only hospice care or not to stop treatment that prolongs life.	Education, value determination, document decision	Online resource
Looking Ahead: Choices for Medical Care When You're Seriously Ill/Informed Medical Decisions Foundation	Patients with serious/ advanced illness	This program is for people with a serious illness that is, or may become, life threatening. This program is also for family members and caregivers. The program describes different types of medical care, such as palliative care and hospice care, and reviews various types of advance directives.	Education, value determination	Available as a DVD, a booklet, and a Web-based program
When you need extra care, should you receive it at home or in a facility?/Ottawa Patient Decision Aid Research Group	Patients with serious/ advanced illness	This decision aid helps patients decide whether they would like to receive care at home or in a facility	Education, value determination, document decision	Downloadable pdf

Table D2. List of identified relevant studies from trial registries

Trial # (Registry)	Trial Name	Investigators Study Sponsor Collaborators
NCT01190488 (ClinicalTrials.gov-Completed)	Feasibility of an advanced care decision aid among patients and physicians	D Matlock University of Colorado, Denver
NCT01325519 (ClinicalTrials.gov-Recruiting)	A prospective randomized trial using video images in advanced care planning in seriously ill hospitalized patients	AE Volandes Massachusetts General Hospital
NCT01527331 (ClinicalTrials.gov-Recruiting)	A prospective trial using video images in advance care planning in hospitalized seriously ill patients with advanced cancer	AE Volandes Massachusetts General Hospital Stanford University
NCT01589120 (ClinicalTrials.gov-Recruiting)	Using videos to facilitate advance care planning for patients with heart failure (VIDEO-HF)	AE Volandes Massachusetts General Hospital University of Colorado, Denver, Vanderbilt University, South Shore Hospital, Brigham and Women's Hospital, Boston Medical Center
NCT01445145 (ClinicalTrials.gov-Completed)	An exploratory study of the use of five wishes as a tool for advanced care planning in young adults with metastatic, recurrent, or progressive cancer or HIV infection	L Wiener National Cancer Institute
NCT01105806 (ClinicalTrials.gov-Ongoing, not recruiting)	Cardiopulmonary resuscitation (CPR) video to enhance advance care planning in advanced upper gastrointestinal cancer patients	E O'Reilly Memorial Sloan-Kettering Cancer Center Massachusetts General Hospital, Mount Sinai Hospital, New York
NCT01391429 (ClinicalTrials.gov-Unknown)	Testing a video decision support tool to supplement goals-of-care discussions	M Paasche-Orlow, A Volandes Boston Medical Center
NCT01653938 (ClinicalTrials.gov-Recruiting)	A trial of a CPR video in heart failure patients	A Volandes Massachusetts General Hospital
HSRP20122281 (HRS-Proj – Ongoing)	Using videos to facilitate advance care planning for patients with heart failure	A Volandes Massachusetts General Hospital John D. Stoeckle Center for Primary Care Innovation, National Heart, Lung, and Blood Institute
HSRP20104051 (HSRProj – Ongoing)	Improving end-of-life care for cancer patients with video decision aids	A Volandes Massachusetts General Hospital Agency for Healthcare Research and Quality

Appendix E: Examples of Advanced Care Planning Tools That Did Not Meet Definition of Decision Aid

Organization	Name of Tool	Target Population	Description	Purpose of Tool	Tool Format	Accessed	URL
Gold Standards Framework	'Thinking Ahead' – GSF Advance Care Planning Discussion	General planning before a medical event or terminal illness	Advance Statement should be used as a guide, to record what the patient DOES WISH to happen, to inform planning of care. This is a 'dynamic' planning document to be adapted and reviewed as needed and is in addition to Advanced Directives, Do Not Resuscitate plan, or other legal document.	Document patient wishes and prompt discussion	Downloadable form	Gold Standards Framework	http://www.goldstandardsframework.org.uk/advance-care-planning
ALS Association	ALS Respiratory Decisions	Patients with ALS	This pamphlet is designed to help the person with ALS make the choice or choices appropriate for them and their family. This information is for your education only and is not intended to replace the medical advice of your personal physician or other members of your health care team.	Document patient wishes and prompt discussion	Downloadable guide	The ALS Association Jim "Catfish" Hunter Chapter	http://webnc.alsa.org/site/DocServer/brochure_RespiratoryDecisions.pdf?docID